

## Use of a Population Based Cancer Registry to Monitor Trends of Incidence of Childhood and Adolescent Cancers in Kampala, Uganda

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### ABSTRACT

**Background:** In high-income countries, haematological malignancies are the most common. World Age-Standardized Incidence Rates in Ireland averaged 142 cases per million children per year, higher than European average and lower than US average. In Africa, distribution of childhood cancers is quite similar, commonest being Kaposi sarcoma (KS), and Burkitt's lymphoma and Hodgkin Lymphomas (HL). Among adolescent in Zimbabwe, leukaemia has highest incidence rates then osteosarcoma, Non-Hodgkin lymphoma (NHL) and KS. Only 30 functional cancer registries exist currently in 23 countries in Africa. Yet these are vital in planning cancer control programs. This study sought to describe the incidence of cancer among children and adolescents in Kyadondo County, Uganda from 2009 to 2014 using a population based cancer registry which is necessary for planning of cancer control programs.

**Methods:** Descriptive cross-sectional study which involved review of data from Kampala Cancer Registry that gathers information on cancers diagnosed within Kyadondo County, Uganda. Study population was children (0-14 years) and adolescents (15-19 years) diagnosed with cancer from January 2009 to December 2014.

**Results:** 752 patients, 71.7% (n=539) were children (0-14 years) and 29.3% (n=213) were adolescents (15-19 years) diagnosed with cancer between January, 2009 and December, 2014. Among the children, Hodgkin lymphoma was 21%, 12% Kaposi Sarcoma, 9% nephroblastoma, 7% retinoblastoma, 11% unspecified malignancies and 40% others. Among the adolescents, 20% were Kaposi Sarcoma, 18% Non-Hodgkin lymphoma, 8% Hodgkin lymphoma, 7% Hodgkin Lymphoma, 6% Chronic Myeloid leukaemia and 41% other malignancies.

**Significance:** Cancer common among children compared to adolescents. Nephroblastoma and retinoblastoma cases were found in only the children. Cancer registries are potential sources of cancer surveillance data. National cancer registries should be put in place to provide timely information on the changing incidences of childhood and adolescent cancers as well as other adult cancers. This can inform cancer control programs.

## Introduction

Cancer may be relatively rare in childhood compared to later in life but is one of the more frequent causes of non-traumatic deaths in children worldwide. Cancer continues to be the leading disease-related cause of death among children and adolescents in the United States.

The common malignant diseases of childhood are leukaemia, lymphomas, tumors of the central nervous system and embryonic solid tumors (such as nephroblastoma and neuroblastoma) whereas among the adolescents, sarcomas of bone and soft tissue, and tumors of the male and female genital tracts. Moreover, the epithelial tumors (carcinomas), so prevalent in adults, occur (but at much lower frequencies) in adolescents (Siegel et al., 2014) (Petridou et al., 2008).

In Africa, the distribution of childhood cancers is quite similar. The commonest being Kaposi sarcoma, Burkitt's lymphoma, retinoblastoma, leukaemia and Hodgkin lymphomas (Stefan, 2015)(Stefan, 2015)(Mostert et al., 2012; Stefan, 2015). The distribution of childhood cancer in Africa has changed in the past decade due to the Human Immunodeficiency Virus (HIV) epidemic and the appearance of Kaposi sarcoma. Southern Africa remains the region mostly affected by this HIV related malignancy (Chintu, Athale, & Patil, 1995; Stefan, 2015)

The current patterns in Uganda are not available, but trends in the 1990's showed that lymphomas (35.8%), Kaposi sarcoma (25.1%), leukaemias (6.9%) nephroblastoma (Wilms' tumour) (6.2 %), and retinoblastoma (4.8%) had the highest incidence rate (D. M. Parkin et al., 2010; Wabinga et al., 2014)..

Population-based cancer registration is developing slowly in Africa, and there are now only 30 functioning population-based registries in the continent. Many countries in Africa do not have a cancer registry and, from those who do, 16 registries submitted and only 5 registries (31%, 5/16) from 5 countries have been selected to contribute to the data published in Volume IX of Cancer Incidence in Five Continents (CI5) (D M

Parkin, Whelan, Ferlay, Raymond, & Young, 1997). The share of the world population covered in this volume (Vol. 9 CI5) is 11%, which is distributed as follows: Africa, 8.8 million (1%); South and Central America, 23 million (4%); North America, 258.5 million (80%); Asia, 152.3 million (4%); Europe, 238.8 million (33%) and Oceania, 23 million (73%).

This study describes the incidence rates of cancer among children and adolescents in Kampala, Uganda from 2009 to 2014.

## Methods

This was a retrospective descriptive cross-sectional study in which we reviewed cancer patients' data entered into the Kampala Cancer registry from January 2009 to December 2014. The Kampala Cancer Registry (KCR) is statutorily empowered to collect incidence and follow-up data on cancer patients in the Republic of Uganda, and to report non-identifiable summary data on those patients.

Kyadondo County is located in central Uganda and is composed of Kampala City and Wakiso District. According to the 2014 Uganda population census results, Kyadondo County had a population of 3,523,910 people of which 32.2% were children (0-14 years) and 10% were adolescents (15-19 years). The sex ratio for the whole population was 100.5 males per 100 female. The most common tribe is Ganda. Children up to the age of 14 years as well as adolescents aged 15-19 years of age (age at diagnosis) diagnosed with cancer from various health facilities in Kampala and Wakiso districts.

A soft copied data extraction questionnaire (generated by Epidata 3.1) was used to capture patients' data from the Kampala cancer. Data entry was done on separate questionnaires (Double entry using Epidata 3.1) which were compared to eliminate errors during data entry. Data analysis was done using STATA 13 and Microsoft Excel 2013. The study did not involve human participants so no consenting were needed. The Director of Kampala Cancer Registry at Makerere University Pathology

Department gave approval for collection of data. The study had minimal risk, in which there was no loss of privacy of patient information from the Kampala Cancer registry.

## RESULTS

**Demographics:** A total of 752 patients were included in the sample i.e. children (0-14 years) and adolescents (15-19 years) who had been diagnosed with cancer between January, 2009 and December, 2014. 71.7% (n=539) were children (0-14) years while 29.3% (n=213) were adolescents (0-15) years of age. According to fig. 1, 56.4% (n=304) of the children were male whereas 43.9% (n=235) were female. Among the

adolescents, 50.2% (n=107) were female whereas 49.8% (n=106) were male.

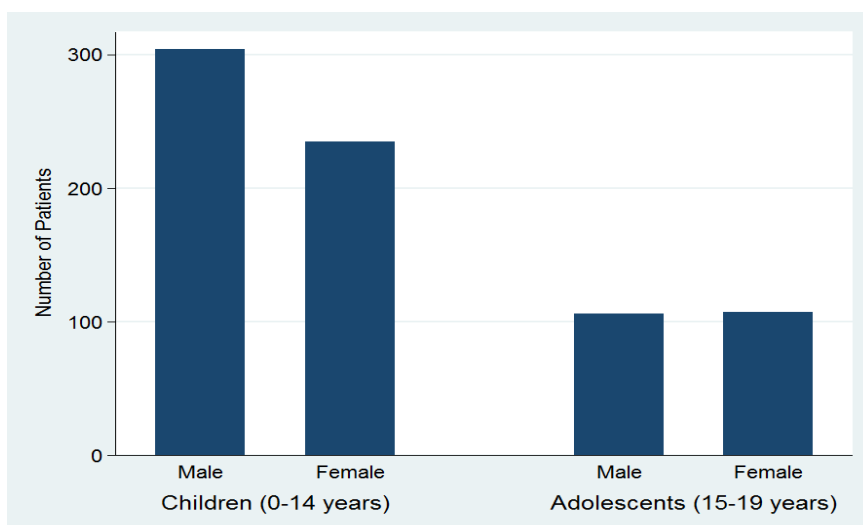
### Most commonly diagnosed childhood and adolescent cancers

#### Cancers in the population aged 0 to 19 year:

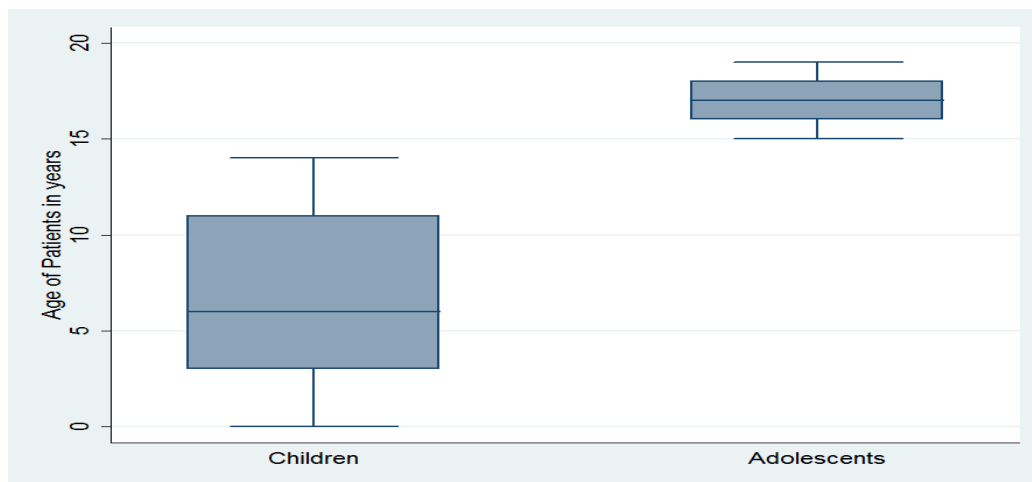
According to fig. 3, Non-Hodgkin Lymphoma was the most commonly diagnosed with 131 cases among population aged 0-19 years, followed by Kaposi Sarcoma with 107 cases, Unspecified Malignant Neoplasms with 92 cases, and both Rhabdomyosarcoma and Hodgkin Lymphoma with 40 cases each respectively The other cases of cancer totalled to 342 cases.

**Table I: Mean and median of the ages of the children and adolescents diagnosed with cancer, Kyadondo County, Uganda (2009 to 2014)**

	Children (0-14 years)		Adolescents (15-19 years)		Total
	Male %(n)	Female %(n)	Male %(n)	Female %(n)	
<i>Sex</i>	56.4(304)	43.9(235)	49.8(106)	50.2(107)	752
<i>Mean age (S.D)</i>	6.94 (4.25)		17.1 (1.38)		9.8 (5.9)
<i>Median age</i>	6		17		10



*Figure 1: Numbers of children and adolescents by gender who were diagnosed with cancer in Kyadondo County, Uganda; 2009-2014*



*Figure 2: Distribution of ages of the children and adolescents who were diagnosed with cancer Kyadondo County, Uganda; 2009-2014*

**Cancers among children:** According to fig. 3, Non-Hodgkin lymphoma is the most common cancer among the children aged 0-14 years with 113 cases, followed by Kaposi Sarcoma with 65 cases, Unspecified Malignant Neoplasms with 59 cases, Nephroblastoma with 49 cases and Retinoblastoma with 40 cases respectively. The other cancers were 213 in total. Nephroblastoma and Retinoblastoma cases were found in only the children.

**Cancers among the adolescents:** According to fig. 3, Kaposi Sarcoma is the most common cancer among the adolescent with 42 cases between 2009 and 2014, followed by unspecified malignant neoplasms with 33 cases, Non-Hodgkin lymphoma with 18 cases, Hodgkin lymphoma with 15 cases and Chronic Myeloid leukaemia with 14 cases respectively. The other cancers totalled to 91 cases.

#### **Age Standardised Incidence Rates (ASR)**

The age standardised incidence rate per 1,000,000 were calculated for the children (0-14 years), adolescents (15-19 years) and for a combination of both age groups (0-19 years) for each of the individual cancers from 2009 to 2014. The ASR were standardised to the WHO world standard population. Table II shows the age standardised incidence rates of the childhood and adolescent cancers by gender in Kyadondo County, Uganda from 2009 to 2014.

According to fig. 6, the incidence of Retinoblastoma in children was higher than that of nephroblastoma 2009, but the trend has changed over time from 2011, with the incidence of nephroblastoma being slightly higher than that of retinoblastoma.

In 2014, the incidence rates of retinoblastoma and nephroblastoma in Kyadondo County were 0.2 and 1.4 per 1,000,000 children respectively.

#### **Relationship between childhood and adolescent cancers**

Nephroblastoma and retinoblastoma were common among the children only. The other types of cancer were distributed among the children and adolescents. There was no cancer that was found to be associated with only the adolescents.

#### **Mode of diagnosis of the childhood and adolescent cancers**

According to fig. 7, 55% (n=414) were confirmed by Histology of the primary, 29.4% (n=221) by clinical examination only, 6.9% (n=52) by laboratory tests, 2.3% (n=17) by cytology, 1.1% (n=8) by radiology and 0.3% (n=2) using tumor markers. 5% (n=38) of the cases retrieved from the cancer registry was obtained from death certificates.

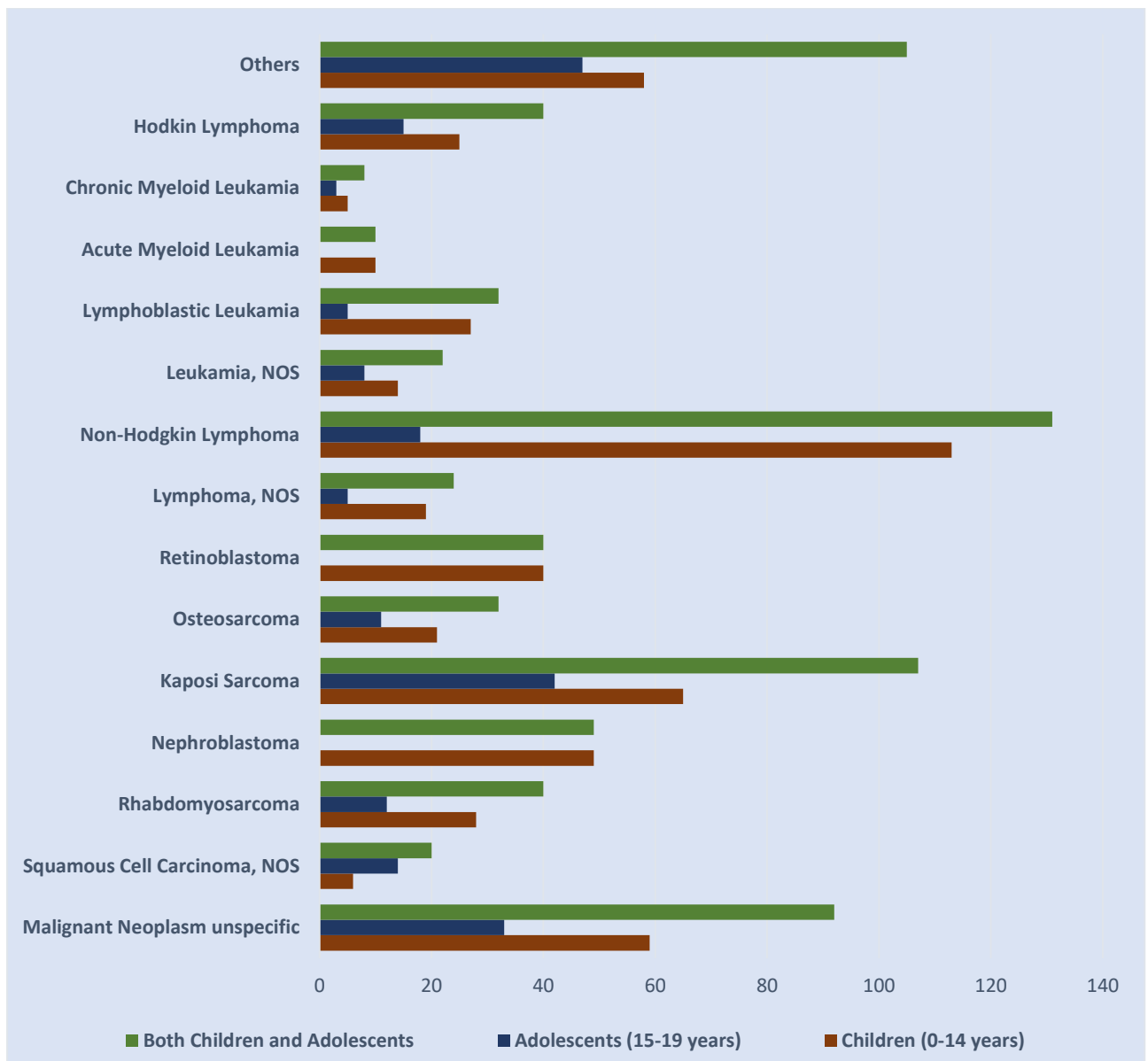


Figure 3: Distribution of childhood and adolescent cancers by age group in Kyadondo County, Uganda: 2009 and 2014.

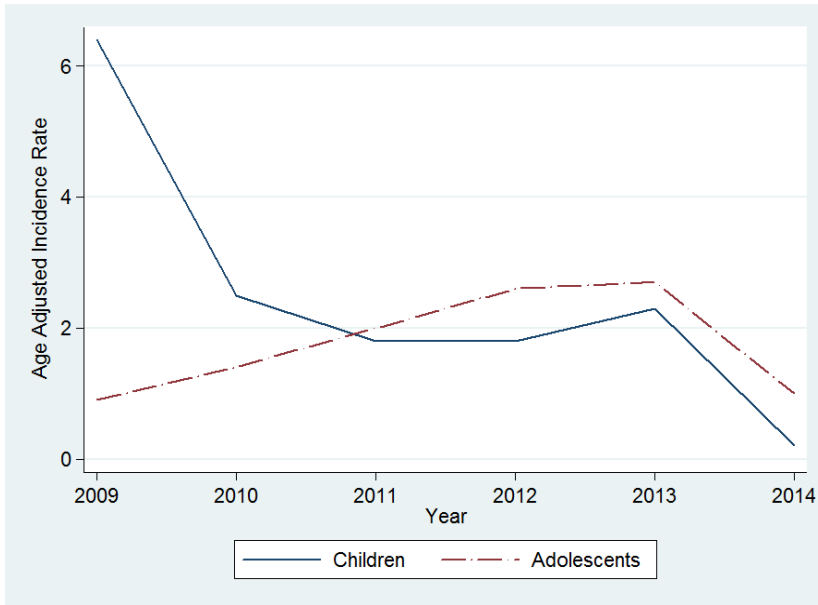


Figure 4: Trends in age standardised incidence rates of Kaposi Sarcoma among children and adolescents, Kyadondo County, Uganda: 2009-2014 (n=752)

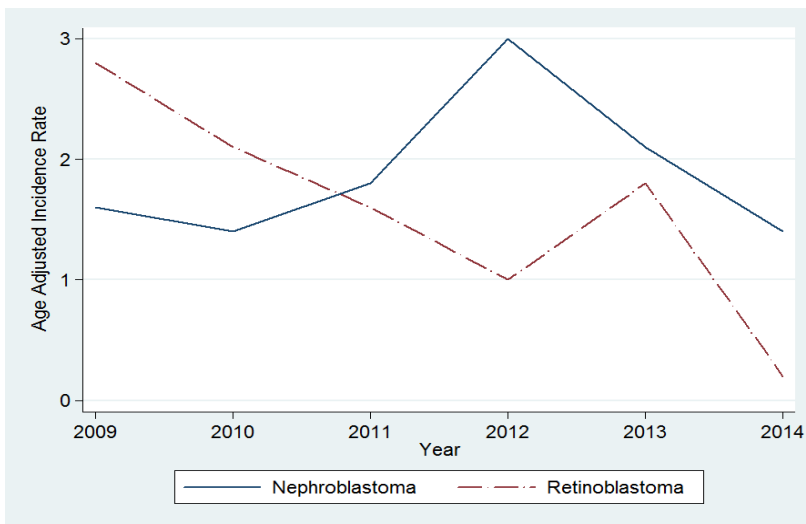


Figure 5: Trends in age standardised incidence rates of Retinoblastoma and Nephroblastoma among children (0-14 years) in Kyadondo County, Uganda: 2009-2014

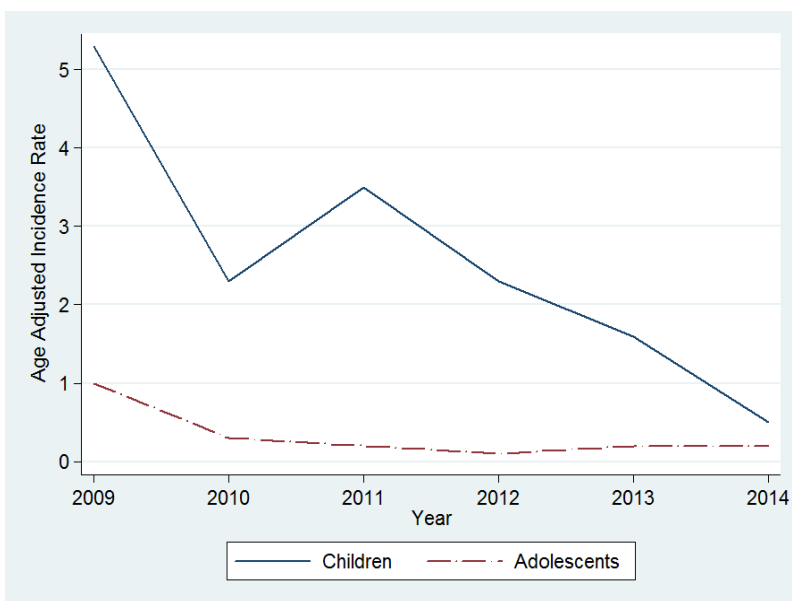


Figure 6: Trends in age standardised incidence rates of Burkitt's Lymphoma among children and adolescents, Kyadondo county, Uganda 2009 to 2014 (n=752)

## **DISCUSSION**

### **Among children**

In studies that were carried out in other African countries, it shows that the results obtained from this study are similar in terms of the most common cancers among the children.

In studies done in Kenya and Rwanda that used population based cancer registries, the most common were Non-Hodgkin lymphoma, leukaemia, Kaposi Sarcoma and nephroblastoma respectively (Mostert et al., 2012; Stefan, 2015). In West Africa, Mali, Non-Hodgkin lymphoma, Kaposi Sarcoma, leukaemia and Hodgkin lymphoma are the most common cases of childhood cancers. In a study done in Malawi using a national cancer registry, it was found that Non-Hodgkin lymphoma, Kaposi Sarcoma and Nephroblastoma were the most common cancer among the children (Stefan, 2015).

The findings from this study differed from that in countries outside Africa. Haematological malignancies, solid tumors brain tumors were the most common cases of childhood and adolescent cancers (Howard et al., 2007; Link & Donaldson, 2003; McNally et al., 2001; D. M. Parkin, Kramaroya, & Draper, 1998; Siegel et al., 2014). This was a trend common among the developed countries. In United State of America, leukaemias, CNS tumors and lymphomas were the most common (Yamamoto & Goodman, 2008). In North West Iran using a population based cancer registry, the findings showed that leukaemias, CNS tumors and neuroblastoma were the most common (Fathi, Bahadoram, & Amani, 2015). The distribution of childhood cancer in Africa has changed in the past decade due to the human immunodeficiency virus (HIV) epidemic and the appearance of Kaposi sarcoma. Southern and East Africa remains the region mostly affected by this HIV related malignancy (Stefan, 2015).

### **Among adolescents**

The trends of adolescent cancers in Uganda were quite similar to those in other African countries although Kaposi Sarcoma was the most incident which was not the case with other African

countries (Stiller, 2007). This study found out that Kaposi Sarcoma had the highest incidence rates followed by Non-Hodgkin lymphoma and Chronic Myeloid Leukaemia respectively. In comparison to other studies in Africa, in Zimbabwe, leukaemia, osteosarcoma, Non-Hodgkin lymphoma and Kaposi sarcoma had the highest incidence rates (Stiller, 2007). Non-Hodgkin lymphoma and bone tumors were the most common in Algeria. The incidence of the most common adolescent cancers obtained from this study varied from those of countries outside Africa. In Oceania countries that is New Zealand and Australia, Melanomas are the most common followed by Non-Hodgkin lymphomas, leukaemia, bone tumors and CNS tumors (especially Ependyoma) which also had high incidence rates respectively (Stiller, 2007). In south and East Asia, generally the incidence of cancer among children is low. Above all, leukaemia, Non-Hodgkin lymphoma, bone tumors and CNS tumors have high incidence rates (Stiller, 2007). In West Asia, Non-Hodgkin lymphoma has the highest incidence, followed by leukaemia, bone tumors and thyroid tumors which quite rare in other regions of the world. In the United State of America, Non-Hodgkin lymphoma, leukaemia, gonadal tumors (particularly Germ Cell tumors) and thyroid tumors have high incident rates (Stiller, 2007). In European countries, Non-Hodgkin lymphoma, CNS tumors (Astrocytoma), soft tissue tumors (Rhabdomyosarcoma) and melanoma have high incidence rates respectively.

### **Contrast between childhood and Adolescent cancers**

The results of this study were comparable to others studies and showed that nephroblastoma and retinoblastoma were common among children and were rare among adolescents. Leukaemia and lymphomas cut across the children and adolescents. Cancer may be relatively rare in childhood compared to later in life but is one of the more frequent causes of non-traumatic deaths in children in worldwide (Stack et al., 2007).

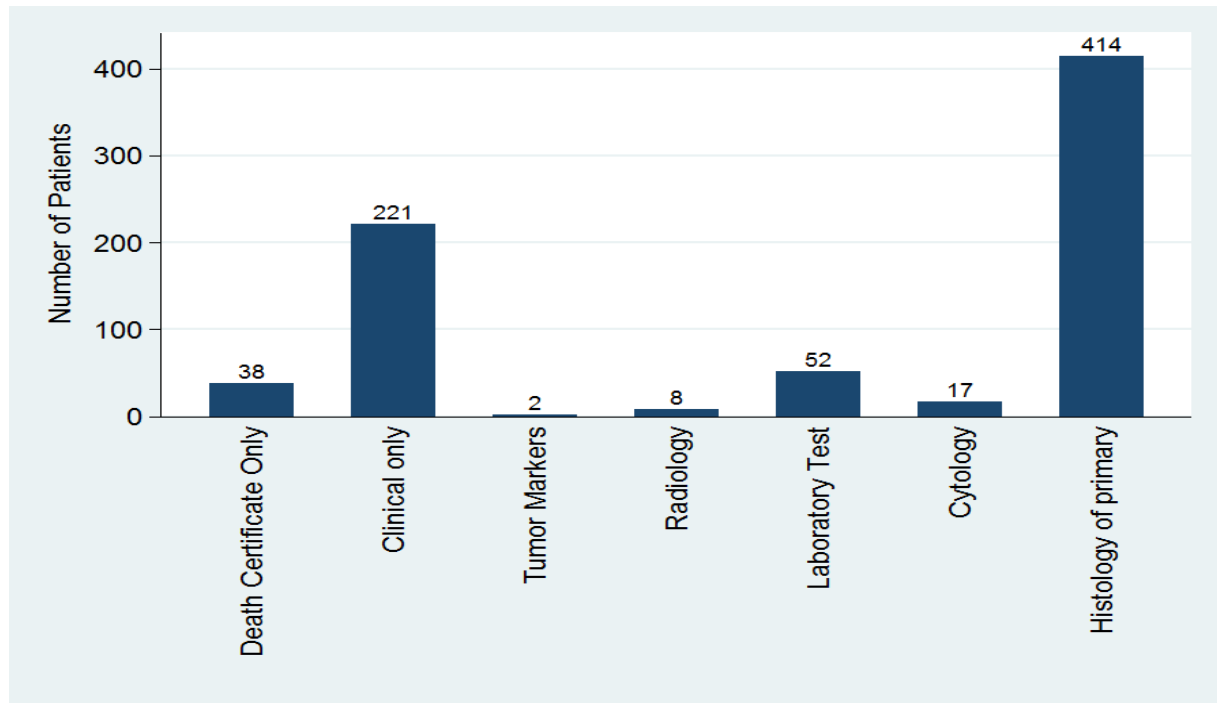


Figure 7: Basis of confirmation of the diagnosis of childhood and adolescent cancers, Kyadondo County, Uganda, 2009-2014 (n=752)

The common malignant diseases of childhood are leukaemias, lymphomas, tumors of the central nervous system and embryonic solid tumors (such as nephroblastoma and neuroblastoma) which are replaced in relative frequency by sarcomas of bone and soft tissue, and tumors of the male and female genital tracts. Moreover, the epithelial tumors (carcinomas), which are so prevalent in adults, occur (but at much lower frequencies) in adolescents (Stack et al., 2007).

## CONCLUSION

The spectrum of cancers in adolescents reflects a transition. Carcinomas which are so prevalent in adults occur but at lower frequencies in adolescents. Study results are comparable to others studies indicating that nephroblastoma and retinoblastoma were common among children and not adolescents. Leukaemia and lymphomas cut across both children and adolescents.

## RECOMMENDATION

National cancer registries should be put in place to provide timely information on the changing incidences of childhood and adolescent cancers. New prospective studies should be done on children and adolescent cancers. Further studies should be done to cover a wide population size.

## Limitations

Some of the patients' information from the database were missing, but this did not affect the analysis of the data obtained from the registry.

## Conflict of interest

This study has no conflict of interest.

## Author contributions

- Abila Derrick Bary: Principal Investigator of the research study and corresponding author.
- Prof. Henry Wabinga: Supervisor and Mentor
- Ass. Prof. Andrew Livex Okwi: Supervisor and Mentor



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